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Prolonged grief: Applying the evidence in the primary care setting

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Contents

Key messages	1
Introduction	2
What is prolonged grief?	2
Identifying prolonged grief	3
Treating prolonged grief	4
The role of primary health care providers	5
A public health approach	6
Clinical guidelines and standards.....	7
Building primary care capacity to detect, refer and treat prolonged grief	8
Conclusions	9
References	10

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Key messages

- ❖ An estimated 5-10% of bereaved individuals are at risk of developing prolonged grief: an extreme, debilitating grief that impairs functioning and mental and physical health.
- ❖ Prolonged grief is usually not diagnosed until at least six months after bereavement. It is characterised by preoccupation with the deceased; neglect of self-care; withdrawal from relationships and activities; somatic symptoms; and sleep and mood disturbances.
- ❖ Whether prolonged grief is a distinct psychopathology or part of a continuum of 'normal' grief is a matter for debate in the international academic literature. Nevertheless, there is broad agreement among Australian experts that some grief requires additional support.
- ❖ Triggers for prolonged grief include intrapersonal factors such as a history of trauma, mental illness or other significant losses; interpersonal factors such as exceptionally close, dependent or problematic relationships between the deceased and the bereaved; and situational factors such as a sudden, unexpected death or the death of a life partner or child.
- ❖ For deaths resulting from chronic, life-limiting illness, there are opportunities to reduce the risk of prolonged grief. If sensitively introduced and facilitated, earlier conversations around end-of-life care planning can help prepare the patient and carers for the death, relieve uncertainty about decision-making, and promote communication. Palliative care can support carers and reduce distress and trauma relating to the events around their loved one's death.
- ❖ Systematic, predictive screening of all recently bereaved people is not recommended. However, the use of standardised, validated tools to diagnose prolonged grief in those who have persistent signs and symptoms can assist in appropriate referral for treatment.
- ❖ Generic psychotherapy and the use of anti-depressant medications alone are unlikely to be sufficient to address bereavement-related distress. Instead, specialist treatments are required that address specific issues around loss, separation, identity and meaning in life.
- ❖ A public health model of bereavement support is designed to direct services where they are most needed. GPs can be supported through appropriate information, skills and strong connections with services. There is a need for increased public awareness of prolonged grief to improve recognition and help-seeking by affected people.
- ❖ General Practitioners (GPs) are often the first point of contact for people at risk of, or experiencing, prolonged grief and therefore have a crucial role in correctly identifying and referring patients requiring treatment.
- ❖ Primary Health Networks (PHNs) are well placed to promote better care for prolonged grief through activities such as commissioning new services, coordinating (and facilitating access to) existing services and capacity building in the primary health workforce. The important place of PHNs in end-of-life care and bereavement support is underlined by the recent federal *Greater Choice for At Home Palliative Care* measure.

Introduction

Bereavement – the loss of a loved one through death - is a normal, common human experience. Most people adapt to their loss over time. For a few, however, grief can become extreme and persistent, leading to mental and physical ill health. Researchers have given this type of grief a variety of labels; here we refer to it as *prolonged grief*.

Recent Australian research including a literature review and interviews and discussion groups with 30 academic and clinical experts concluded that (1) prolonged grief is distinct from depression, anxiety and traumatic stress; and (2) prolonged grief requires additional support.¹ Among its recommendations, this research highlighted a need for primary health care professionals to have access to information on prolonged grief. Consequently, this issues paper was commissioned by the Australian Government Department of Health.

General practitioners (GPs) were identified as the starting point for one of the three main care pathways for prolonged grief. Participants in the interviews saw GPs as important gatekeepers who have a crucial role in correctly identifying people and referring them for treatment. The central role of the primary health sector in supporting mental health care is confirmed in recent policy.

Primary Health Networks (PHNs) have an expanded role in mental health care as part of the *Australian Government Response to Contributing Lives, Thriving Communities – Review of Mental Health Programmes and Services*.² Approximately \$1.030 billion has been allocated in 2016-17 under the PHN Grant Programme to support the provision of primary mental health services under a best-practice stepped-care approach.³

In addition, PHNs are the focus for the *Greater Choice for At Home Palliative Care*⁴ measure announced in May 2017 by the Australian Government Department of Health. This measure acknowledges carers' needs for support before and after death. Funding will support up to ten (10) PHN pilot site locations.

This issues brief is intended to guide health service planners and policy makers within PHNs who are undertaking activities relating to prolonged grief. Such activities might include commissioning of services; coordination of activities; and/or capacity building in the primary care workforce. The paper begins with a definition of prolonged grief and summarises the evidence about identification and treatment. This is followed by a discussion of how this evidence can be applied in the primary care setting.

What is prolonged grief?

Prolonged grief is defined as:

*“... extreme and abnormal grief, characterised by a yearning and longing for the deceased that impacts negatively on a person’s relationships, employment and life”.*⁵

Prolonged grief is associated with a number of symptoms and functional impairments: intense yearning for, or preoccupation with, the deceased; avoidance of the reality of the loss; sleep and mood

disturbances; somatic symptoms; neglect of self-care; withdrawal from social and family activities; and inability to engage with life.¹ It is generally accepted that these symptoms persist for at least six to 12 months following bereavement.^{6, 7, 8} Unlike ‘normal’ grief, prolonged grief does not tend to resolve spontaneously; people who do not receive care may continue to suffer adverse impacts on health and quality of life for many years.¹

Whether prolonged grief is a distinct psychopathology or part of a continuum of normal grieving is still a matter for debate.^{9, 10, 11} The most recent edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*⁶ recognised that bereavement-related grief can become clinically significant, but stopped short of including it as a formal diagnosis. Instead, *Persistent Complex*

Bereavement Disorder was listed as a condition requiring further study.

Prolonged grief affects between 5% and 10% of bereaved individuals.^{8, 12, 13, 14, 15} Assuming that five people are bereaved by each death in Australia, it was estimated that in 2013 there were just over 44,000 people in this country who may have been experiencing prolonged grief.¹

Identifying prolonged grief

There are four key time periods in the life of a bereaved person, each with its own challenges. If the death is expected, the *end-of-life* period can be demanding and stressful. The *bereavement* itself may be disturbing, especially if the death is sudden or violent (even in the late stages of a terminal illness, the death of a loved one can come as a shock, especially if there is a history of relapse and remission). In the *immediate, post-bereavement* period, 'normal' grief can be intensely distressing, with adverse consequences for mental and physical health. Finally, if high levels of suffering and impairment persist *beyond six months post-bereavement*, the person may be considered to have prolonged grief.

Experienced clinicians can recognise factors that might trigger prolonged grief. *Intrapersonal* risk factors include a history of abuse or other trauma; previous significant losses; or pre-existing mental illness. *Interpersonal* risk factors include a high degree of dependency or centrality of the deceased to the bereaved person's life; a problematic relationship between the deceased and the bereaved; and a lack of other social supports. *Situational* risk factors relate to the nature of the bereavement. Prolonged grief may be more likely if the deceased is a child or life partner of the bereaved; or if the death is sudden, violent or unexpected. The available evidence does not support systematic screening of all recently bereaved persons, or people who are soon to be

bereaved by an expected death, in order to predict the likelihood of developing prolonged grief.¹ However, there is merit in using standardised, validated tools to assess those who have persistent signs and symptoms. Interventions targeting those already having difficulties with their grieving have demonstrated preventative impacts.¹⁶

In the case of expected deaths from chronic, life-limiting illness, there are actions that health professionals can take that may protect carers against prolonged grief.¹ For some patients and carers it may be useful to create an opportunity for people to acknowledge and start dealing with anticipatory grief. Facilitated conversations or family meetings, if sensitively handled, can help prepare patients and carers for the death. Documenting the patient's wishes for end-of-life care in an Advance Care Plan may relieve carers of uncertainty and pressure to make difficult decisions quickly, promote communication within the patient's family, and alleviate guilt and doubts later on. Events occurring around the time of death are likely to be remembered by carers and influence grieving. Providing accurate information to the family about what happens when someone is dying, and ensuring that the patient is treated with dignity and respect at all times, can help protect them from distress and trauma.¹

The involvement of palliative care services can help ensure a more peaceful and dignified death.

Treating prolonged grief

Any treatment for prolonged grief needs to target the distinctive symptoms and functional impairments associated with the condition. Specific attention is required to the person's distress around loss, separation; identity and meaning in life.¹ Specialist treatments are more effective than generic psychotherapy approaches.^{17, 18}

In Australia, the main providers of specialist treatment for grief-related issues are bereavement counsellors. They may be employed by palliative care services or community-based not-for-profit organisations or work in private practice, and typically have qualifications in social work, nursing, psychology or similar, with extra qualifications relating to grief counselling and intervention. Other important groups of providers involved in bereavement support are psychologists, social workers and nurses.

At least two evidence-based, structured approaches to deal with prolonged grief have been developed. *Complicated Grief Treatment* is a structured program developed by the Center for Complicated Grief at Columbia University, delivered over 16 sessions by an accredited counsellor. The therapy directly addresses issues around attachment, separation and loss and draws on the dual-process model of bereavement.¹⁹ The goal of therapy is to encourage people to find a balance between time for grieving and time for looking to future goals and engaging in enjoyable and productive activities.

Another structured approach has been developed by the Traumatic Stress Clinic at the University of New South Wales. The therapeutic components are similar to *Complicated Grief Treatment*, and have been demonstrated to be effective in research trials.⁹

The behavioural components of specialised grief treatments – elements such as exposure and behavioural activation – have been shown to be particularly effective.¹⁶ Other key elements of these therapies are psychoeducation, processing of the loss (e.g. by recounting the story of the death repeatedly), social support, goal setting and reducing avoidance behaviours.²⁰ The field is developing rapidly and it will be important for clinicians to keep up-to-date with new and emerging therapies.

There have been few randomised controlled trials to inform the use of pharmacotherapy for prolonged grief.²¹ Reviewers have concluded that selective serotonin reuptake inhibitors and tricyclic antidepressants may be effective²² but treatment with benzodiazepines is not recommended as these drugs can hinder psychological adaptation to bereavement.²⁰ Specialised bereavement therapies should be the first line of treatment, with antidepressants used as an adjunct where necessary; there is some evidence that they improve adherence and enhance patients' responses to specialist therapies. Earlier treatment with antidepressants may be warranted where there is comorbid depression and/or suicidal ideation.²⁰

According to Phoenix Australia (the Centre for Posttraumatic Mental Health), if medication is required for the treatment of prolonged grief, newer antidepressants should be considered as the first choice and should only be delivered as an adjunct to psychological intervention.²³ It is recognised that clinical management will ultimately be a decision for the treating GP based on a holistic understanding of the patient's history, needs and condition.

The role of primary health care providers

Primary health care professionals have an important role to play in detecting those at risk of, or suffering from, prolonged grief and ensuring they have access to appropriate treatment. For many people, the pathway into bereavement services will begin with a visit to the GP. Other common pathways are through contact with palliative care services and self-referral.¹

Based on current definitions, prolonged grief cannot be diagnosed until at least six months after the death. By this time, those carers and family members whose loved ones received palliative care may have lost contact with the services and supports they had previously accessed. Self-referral is the main mode of entry into bereavement counselling services, but this assumes the patient is capable of recognising what is going on and knows where to access help.

Often, people experiencing prolonged grief are not aware that this is what is happening to them. It may be difficult to get family and friends to listen to their concerns, as there is an assumption that grief is something that people eventually work through. The term 'prolonged grief' is not widely known or understood. Some people experiencing prolonged grief become so overwhelmed and isolated that they are incapable of responding to overtures of help, let alone seeking out assistance.

Ideally, the GP will know that the person has experienced a significant loss and will be aware of local services or private practitioners that have expertise in dealing with grief and loss. A specialist skill set is needed in assisting bereaved individuals. It is considered desirable for health professionals to have some additional training, on top of their usual qualifications, in order to address grief-related issues with clients. As indicated above, referral to generic psychological counselling or prescribing anti-depressants alone will most likely be insufficient to address bereavement-related distress.

One option for GPs to refer patients who may be experiencing prolonged grief is via the *Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS (Better Access) initiative*.²⁴

Under the MBS (Better Access) initiative, patients can be referred by GPs to psychologists, psychiatrists and appropriately trained social workers for up to six consultations per year with a Mental Health Treatment Plan. Private practitioners are free to set their own charges, and the patient receives a rebate from Medicare to subsidise the cost. After the first six visits, another four are allowed with a second referral (to a maximum of 10 annually). A range of specific conditions – including bereavement disorder – are eligible for services, and the GP can make the referral.

The additional cost of the private practitioner's service, beyond what Medicare covers, is seen as a potential barrier for some patients.

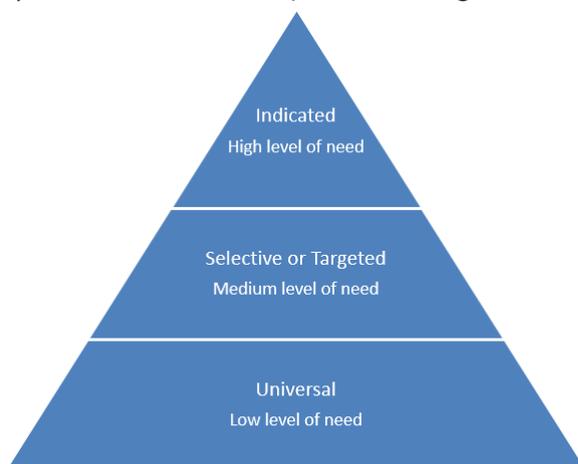
A second option for GPs is referral to local primary mental health services. Under the Primary Mental Health Care Activity of the PHN Grant Programme, funds have been allocated to enable PHNs to lead mental health service planning, commissioning and integration of services at a regional level to improve outcomes for people at risk of, or experiencing, mental illness.³ Funding previously provided through the ATAPS program is now being provided through the PHN funding arrangements. PHNs are expected to work closely with State and Territory governments, GPs, non-government organisations and related services and providers.

A person-centred, stepped care model is central to these mental health care reforms.²⁵ This model of care is consistent with the public health approach to bereavement support.

A public health approach

A public health approach to bereavement support in palliative care was advocated by experts in our recent research¹ and in the literature.²⁶ Such an approach acknowledges that grief does not always require a professional response. Most bereaved people will manage with the support of family and friends. Therefore it is important to target interventions where they are most needed.

Australian researchers have argued in favour of a three-tiered model of care, which is consistent with guidelines proposed by the National Institute for Clinical Excellence (NICE) in the United Kingdom.²⁶ At the first, 'universal' level, all bereaved people should have access to information about bereavement and available supports. At the second, 'selective' or 'targeted' level, non-specialist support would be provided by trained volunteers, community groups and mutual support groups to about a third of bereaved individuals as required (i.e. those at risk of developing complex needs). At the third, 'indicated' level, a small proportion of bereaved people – around 10% – have high level and more complex needs that will require access to professional specialist interventions (refer to the figure below).²⁶



Such a model requires strong partnerships between specialist palliative care and primary health care professionals.²⁶ GPs will need training to recognise those at risk of, or suffering from, prolonged grief and will also require established links with

community supports, bereavement services and appropriately trained private practitioners. Building capacity in primary care will also benefit the many people who are bereaved outside the palliative care context. Rather than increasing demands on the primary care sector, it is likely that appropriate referral and treatment for prolonged grief will reduce visits to GPs for mental illness and somatic complaints due to loss, such as fatigue, sleep disturbances and immune suppression.²⁶ There is also a need to raise public awareness of prolonged grief. Bereavement services generally prefer clients to contact them directly rather than through a third party. Requiring a diagnosis to access care risks 'the medicalisation of sadness'.^{1, p.90} Further, those who choose treatment freely are most likely to benefit. Self-referral based on need is consistent with a public health approach. As well as public awareness, self-referral also depends on availability of bereavement counselling services.¹

Stratifying the population according to need for mental health services is a core element of the stepped care model.²⁵ Stepped care is a system of mental health service provision consisting of a hierarchy of interventions from least to most intensive. In this respect it is broadly consistent with a public health approach to bereavement care. There is little evidence that universal preventative interventions are effective in bereavement¹; therefore, people at risk of prolonged grief would be most likely to enter the stepped care system at the central tiers of the model (i.e. mild to moderate mental illness) although some will present with problems of greater severity. They will require access to specialist support for bereavement and grief-related issues, delivered by appropriately trained counsellors, psychologists, social workers or mental health nurses. At this level of service provision, access is likely to require a referral from a GP, underlining the need for accurate identification and referral.

Clinical guidelines and standards

A recent literature review¹ did not identify any clinical guidelines specific to prolonged grief, but recognised the *Bereavement Support Standards for Specialist Palliative Care Services*²⁷ as the best source of current evidence about the management of bereavement-related health issues. These guidelines were based on a systematic review²⁸, consultation with experts, the results of a survey of Victorian palliative care services and adaptation of previous guidelines. They are targeted at palliative care services and contain no recommendations regarding primary care. However, they do recommend a multi-disciplinary assessment process at intake into palliative care, including assessing the carer's risk of prolonged grief. Those at increased risk would be provided with greater support in the period immediately before the death, and follow-up at around six months after bereavement. At this point, people may be offered more comprehensive assessment and links to community-based supports or, if warranted, referral to specialist treatments.

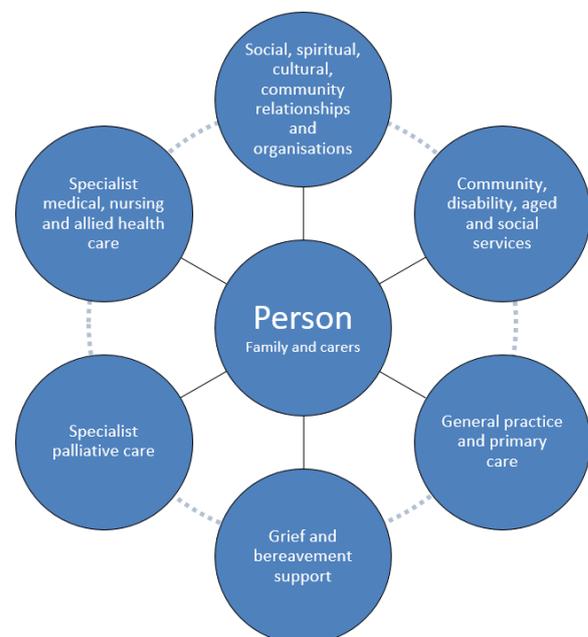
The role of carers as both providers and recipients of care is a guiding principle of the draft *National Palliative Care Strategy 2017*.²⁹ The National Strategy affirms palliative care is a person-centred approach provided in a range of settings by diverse service providers (refer to following figure).²⁹ The document notes that not all patients will require specialist palliative care and there is potential to increase the capacity of other health professionals, including those in primary care, to take a palliative approach. One priority is assessment of needs across all settings, including assessment of carer and family needs.²⁹

According to the *National Palliative Care Standards*, primary care providers play a key role in delivering the palliative approach, which aims:

... to improve the quality of life for individuals with a life limiting illness, their caregiver/s and family. The palliative approach incorporates a concern for the

holistic needs of patients and caregiver/s that is reflected in assessment and in the primary treatment of pain and in the provision of physical, psychological, social and spiritual care.^{30, p.11}

These standards are under revision and the 5th edition is scheduled for release in 2018. The final draft, released for consultation, highlights the importance of caring for the carers (Standard 3) and grief support (Standard 6). Adhering to these standards may improve support for bereaved carers and/or facilitate early access to treatment.



For example, the standards state that carers' needs should be assessed independently and they should be given support to help them fulfil their caring roles and reduce the associated stress. They require plans for dealing with emergency and out-of-hours situations and appropriate information about the signs and symptoms of imminent death. Services should have mechanisms for identifying people experiencing prolonged grief and referring them appropriately. Specialist palliative care services should provide access to trained and skilled staff for bereavement support. These new standards have been mapped onto the previous version as well as other relevant documents such as the Australian

Commission on Safety and Quality in Health Care (ACSQHC) *National Safety and Quality Health Service Standards (Version 1)*³¹ and the ACSQHC *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care*.³²

HealthPathways represent guidelines, agreed at a local level, about the optimal patient pathway for a particular condition. The process by which agreement is reached is critical to the concept.³³ In particular, HealthPathways specify the role of

general practitioners and the role of hospital outpatient clinics. HealthPathways have been developed for bereavement, grief, and loss which identify various ‘complicating factors’, some of which are consistent with known risk factors for prolonged grief. Where in use, these HealthPathways may provide a useful resource for members of the primary care team about bereavement support options in their local community.

Building primary care capacity to detect, refer and treat prolonged grief

Primary health care providers play an increasingly important role in supporting the many Australians now living with chronic illnesses such as cancer, cardiovascular disease and organ failure that will ultimately cause their death. Around 80% of Australians who die in any given year are aged over 65 and the proportion of the population over this age is steadily increasing.²⁹ The primary care sector will need to be equipped to deal with an expected increase in demand for support with end-of-life care and bereavement-related issues, including prolonged grief.¹

PHNs are well placed to support primary health care providers to address the needs of people at risk of, or experiencing, prolonged grief. The potential responses of PHNs can be grouped into three categories: commissioning of new services; coordination of existing services; and capacity building within the community and the primary health workforce.

Commissioning of prioritised health services is a core function of PHNs and one of the national headline indicators of the PHN Performance Framework is mental health treatment rates.³

Commissioning activities relating to prolonged grief might include:

- ❖ Scoping of available bereavement support services within the PHN’s locality

- ❖ Commissioning new bereavement services where required
- ❖ Research to identify innovative bereavement support solutions for special needs groups (e.g. Aboriginal and Torres Strait Islander people, older Australians) or for remote or rural populations
- ❖ Designing, implementing and evaluating models of care for people at risk of, or experiencing, prolonged grief.

Coordination of services for bereaved people is crucial as delayed or inappropriate referral has been identified as a major barrier to service provision for prolonged grief.¹ Improving service integration, particularly with State health services, is a strategic imperative for PHNs. Innovative work is already taking place in several PHNs, for example in end-of-life care.

Coordination activities relating to prolonged grief might include:

- ❖ Documenting and evaluating existing care pathways for bereavement support within the PHN’s region.
- ❖ Developing HealthPathways for bereavement support in cooperation with GPs and local

hospitals (some already exist and could serve as a model)

- ❖ Creating registers of suitably qualified and experienced practitioners who can provide bereavement support, and making these accessible to GPs.

Capacity building in the GP workforce has considerable potential to benefit people at risk of, or experiencing, prolonged grief. Primary care workforce support is another core function of PHNs and a key activity funded through the PHN operational funding stream.

Capacity building activities relating to prolonged grief might include:

- ❖ Providing training for GPs and the primary care workforce in end-of-life care and bereavement support
- ❖ Initiating public awareness campaigns around death, dying and bereavement to increase public recognition of the signs and symptoms of prolonged grief and encourage help-seeking behaviours
- ❖ Acting as a conduit for information to GPs from peak organisations that may represent people with prolonged grief or conduct or compile research into this condition (e.g. CareSearch, Palliative Care Australia, Carers Australia).

Conclusions

An estimated 5-10% of bereaved individuals will experience prolonged grief: ongoing, debilitating grief that interferes with functioning and impairs mental health and quality of life. Currently, prolonged grief is not well recognised or understood either in the community or in the primary health care sector. As GPs are often the first point of contact for people experiencing prolonged grief, there is an urgent need to build capacity in this sector and PHNs are well placed to undertake this work.

The role of primary health care and PHNs in end-of-life care and bereavement support is underlined by

the recent *Greater Choice for At Home Palliative Care* measure. This measure provides funding via PHNs to improve coordination and integration of end-of-life care across primary, secondary, tertiary and community health services. There may be opportunities to draw on this measure and other sources of PHN funding to support activities including commissioning of new services; coordination of existing services; and capacity building in the primary health workforce around services and supports for people experiencing prolonged grief.

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